

Behavioral and Social Sciences Research Coordinating Committee

Minutes of March 9, 2001 Meeting

Attendance

The NIH Behavioral and Social Sciences Research Coordinating Committee met on April 13, 2001 from 9:00 to 11:00 a.m. in the Gateway Building, Room 533. Raynard Kington (OD/OBSSR) presided. Members and alternate members in attendance were: Judy Auerbach (OD/OAR), Bob Croyle (NCI), Bruce Cuthbert (NIMH), Sanford Garfield (NIDDK), Lynne Haverkos (NICHD), Suzanne Heurtin-Roberts (NCI), Peter Kaufmann (NHLBI), Susan Martin (NIAAA), Georgeanne Patmios (OD/OBSSR), Linda Rebling (NCI), Lana Shekim (NIDCD), Richard Suzman (NIA), Martina Vogel-Taylor (OD/ODP), Jim Waverly (FIC), Bob Weller (CSR), and Charles Wells (NIEHS).

*Note that several attendees did not sign-in so the above list is inaccurate.

Guests attending were: David Johnson (FBPCS), Angela Sharpe (COSSA), and Alan Kraut (APS).

Informed Consent with Secondary Research Subjects ("Third-Party Information in Research").

A researcher at the Virginia Commonwealth University was attempting to build a database on the health of twins, and sent a 25-page questionnaire to twins in the state. The father of one twin opened his daughter's mail and was alarmed that she was being asked questions about his mental health and genitalia. After contacting the researcher and IRB, he raised his concerns with the Office for Protection from Research Risks (OPRR), now the Office of Human Research Protections (OHRP). OPRR investigated and in January 2000, found that the IRB failed to follow federal regulations governing research involving human subjects. Specifically, the IRB did not consider that the study included the collection of individually-identifiable, private information on family members, thereby making these persons "human subjects" under the Common Rule and requiring that informed consent be obtained or waived by the IRB.

Since this will be an agenda item at the April 13 BSSR CC meeting, the group had only a preliminary discussion of the issue, including the confusion this has caused in the research community, confusion internally about which rule for human subjects applies, and the impact on IRBs of the JAMA editorial (see <http://jama.ama-assn.org/issues/v285n2/rfull/jlm00025.html>).

BSSR Components of IC Health Disparities Research Plans: NIAMS

For the past few months, individual committee members have presented the behavioral and social science components of their respective IC's Health Disparities Strategic Plans. At this meeting, Dr. Richard Suzman presented NIA's plan and Dr. Susan Martin presented NIAAA's.

The NIA Strategic Plan for Reducing Health Disparities is available at <http://www.nih.gov/nia/strat-planhd/2000-2005/>. Dr. Suzman noted the National Advisory Council on Aging's (NACA) efforts beginning in 1998 to review minority aging research and discussed the ensuing recommendations. He also reviewed the 6 broad initiatives that are the focus of the NIA Behavioral and Social Research Program (Health Disparities; Aging Minds; Increasing Health Expectancy; Health, Work and Retirement; Interventions and Behavior Change; and Genetics, Behavior and the Social Environment) and several ongoing and proposed research initiatives that focus on health disparities. Key points include the NIA-funded NAS activity to update the 1997 publication Racial and Ethnic Differences in the Health of Older Americans, the plans for the recompetition of the Resource Centers for Minority Aging Research (RCMAR), and the availability of a beta version of a CD-ROM on *Minority Aging Research Datasets* developed by ICPSR's

National Computerized Data on Aging (NACDA). This CD-ROM is being developed to be a unique and easily accessible CD-ROM of datasets related to minority aging processes valuable for analyses of health disparities within and across minority groups; to promote research on minority aging by fostering use of the CD-ROM by both experienced and inexperienced researchers; and to stimulate ideas for research projects and publications based on the use of the dataset collection. .

The NIAAA Strategic Plan for Reducing Health Disparities was unpublished and unavailable on the Internet at the time of this meeting. Foci of the plan will include: the epidemiology of alcohol-use disorders and associated disabilities; possible genetic factors contributing to high risk alcohol dependence in certain minority groups; toxic effects of alcohol on organ systems; fetal alcohol syndrome and prenatal alcohol exposure; prevention; health services research; treatment/medications development; the role of alcohol use and abuse in preventing and treating HIV/AIDS; and research infrastructure. (The plan was subsequently published and is available at <http://www.niaaa.nih.gov/about/Disparities01.htm>.)

NCI's "5 A Day for Better Health Program."

Dr. Bob Croyle, NCI, presented NCI's 5 A Day for Better Health Program (see also <http://www.5aday.gov/>). This national program strives to get the public to eat 5 or more servings of fruits and vegetables every day for better health. NCI funds behavior change and communications research to determine strategies that are effective to increase fruit and vegetable consumption. Dr. Croyle shared with the group the program's current newsletter and a recent evaluation report (both available on the above website). NCI is interested in collaborating more broadly at NIH and would like to link related programs at other ICs. Contact Bob Croyle at 301-435-6816.

Next BSSR Lectures

NICHD Study of Early Child Care

Jay Belsky, Ph.D.

Visiting Professor of Psychology

University of London

Birkbeck College

April 17, 2001, 9 a.m.

Neuroscience Building, Conference Room C

Next BSSR CC meeting

April 13, 2001

9:00 - 11:00 A.M.*

Gateway Building, Room 525

7201 Wisconsin Avenue, Bethesda, MD

* The first hour will be devoted to the *Informed Consent with Secondary Research Subjects* issue.